

# Interim Findings on the national PMTCT Pilot Sites Lessons and Recommendations

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February 2002

This report has been produced by the Health Systems Trust for the national Department of Health. It is part of HST's commissioned role to help develop and co-ordinate a research and evaluation programme for the national PMTCT learning sites



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**ISBN #: 1-919743-64-2**

*Funders of the Health Systems Trust include*  
Department of Health (South Africa)  
Department for International Development (UK)  
Henry J. Kaiser Family Foundation (USA)  
Commission of the European Union  
Rockefeller Foundation  
UNICEF

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Acknowledgements: This report would not have been possible without the cooperation and support of many individuals in the national and provincial Departments of Health, as well as managers and service providers at the site level. They are too numerous to mention by name, but we would like to extend our deep appreciation and thanks to them all.

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# EXECUTIVE SUMMARY

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## BACKGROUND TO THE REPORT

This report primarily describes the process, progress and extent of service implementation in the 18 pilot PMTCT sites, so as to help improve the effectiveness and efficiency of PMTCT services and inform any planned expansion of the programme. Data and information is based on discussions and interviews with managers, coordinators and clinicians; site visits; routine statistics; document reviews; and attendance of national PMTCT steering committee meetings.

The report does not provide data on the impact of the programme on HIV transmission or health outcomes, mainly because the programme is still too young for this. However, Section 6 presents and discusses what is currently known about mother-to-child transmission, including the proven efficacy of NVP. It also discusses the effects of different forms of infant feeding on HIV transmission and child health, and raises a number of important policy issues.

## OVERVIEW OF THE PILOT PROGRAMME

193 health facilities (hospitals, midwife obstetric units, community health centers and clinics) are currently part of the national PMTCT pilot programme. They cover approximately 6,090 ante-natal bookings per month, which translates to about 9% of the total number of country-wide bookings.

The full figure for access to PMTCT in South Africa is considerably more. Some provinces have already begun to expand their services, and together with a number of clinical research sites, the full proportion of pregnant women in this country with access to HIV counselling, testing and NVP may be as high as 15%.

The rate at which pregnant women agree to be tested for HIV is currently 51% in the national PMTCT sites. This translates to about 3,133 pregnant women being tested per month, which is a very positive achievement. The testing uptake rate varies tremendously between provinces and sites (ranging from 17% to 90%), and the reasons for these differences are described in this report. Overall, the HIV testing uptake rate is likely to improve over time.

Of the women agreeing to HIV testing, about 30% are HIV positive. On the basis of these VCT uptake and sero-positivity rates, it is estimated that 6,343 HIV positive pregnant women have been identified in the national PMTCT sites. However, the recorded number of HIV positive women who have delivered with the administration of NVP to both mother and baby is 1,932. Some of the reasons for this large difference in numbers are:

- Because HIV testing usually occurs several months before delivery, at any given point in time, the cumulative number of identified HIV positive pregnant women will be more than the cumulative number of deliveries (especially at the beginning of a programme).
- Women accessing the PMTCT service ante-natally may deliver elsewhere.
- An under-recording of statistics in the labour wards.

## **PROGRESS WITH IMPLEMENTATION AND LESSONS LEARNT**

The experience with implementation has varied considerably, with some provinces and sites doing well, whilst others have struggled. Many of the difficulties and constraints to full and effective implementation were identified as being systemic in nature, and relate to the poor functioning of the health care system in general (as opposed to the functioning of the PMTCT programme specifically).

At the core of the differences between provinces and sites are the large inequities in health care infra-structure within the country.

### **Systems and infra-structure**

In order to improve the quality and sustainability of PMTCT services, and to ensure a smooth and effective expansion of the programme, these broader health systems issues must be addressed concurrently. The report lists these challenges under the three headings of human, management and physical infra-structure in Section 7.1 of the report.

#### **Human infra-structure**

Human resources are the bed-rock of a well functioning health system and PMTCT programme. Staffing needs to be adequate in terms of both quality and quantity.

- Minimum staffing levels for midwives, nurses, doctors and lay counsellors need to be established, and the national and provincial Departments of Health, particularly their Human Resource Directorates, must develop and implement a plan to reach these staffing levels.
- Lay counsellors are central to the programme. Some provinces, however, are still not employing them, and many of the 18 sites lack sufficient numbers. The involvement, support and clinical leadership of doctors in some sites also need to be improved.
- The inconsistent management, training and remuneration of different kinds of lay workers within and between provinces needs to be addressed.

- Developing and sustaining staff competencies and attitudes remains an unfinished challenge in most of the current sites. A carefully developed training plan will be essential for the successful expansion of the PMTCT programme.
- Improving the regular support and supervision of front-line staff and the attitudes of health workers (at the same time as developing their knowledge and skills) will be important elements of a comprehensive training strategy.
- The deficiencies in under-graduate nurse and medical training institutions must be addressed as soon as possible so as to reduce the intensity of in-service training required.

### **Management infra-structure**

A functional health system with effective sub-district health management teams capable of integrating community-based, clinic-based and hospital-based services is critical. The ideal sub-district health system would also help integrate PMTCT services into other related health programmes in a way that will maximize efficiency and effectiveness.

- The active interest and support of senior managers in the PMTCT programme has led to faster and more effective implementation in some sites. However, the level and standard of leadership and management varies between the provinces.
- The slow progress with the establishment of a functional sub-district health system capable of integrating PHC delivery needs to be speeded up.
- The areas of management identified in the report as requiring priority attention are human resource management and programme evaluation. There have been no significant problems with the management of supplies and equipment.
- NGOs and local PWA support groups are potentially invaluable role-players within a PMTCT programme. Managers at all levels of the health system need to continue to develop an environment that is more enabling for effective partnerships between government, NGOs and civil society.

### **Physical infra-structure**

Inadequate physical space and privacy has hampered the ability to provide adequate counselling and HIV testing services, as well as intra-partum (childbirth) care in many facilities. In rural sites, the difficulties and expense of simply getting to health facilities remain major barriers to adequate coverage of the programme as well as to adequate continuity of care.

- Plans to upgrade the physical infra-structure of PHC facilities and district hospitals across the country need to be expedited.

## **PMTCT service delivery issues**

Section 7.2 of the report lists the lessons and recommendations that are specific to the PMTCT service. Important issues to highlight include:

- “Counselling” has been too strongly associated with consent for an HIV test, and needs to incorporate a broader set of activities that include: empowering pregnant women with knowledge and information (e.g. about their childbirth,

HIV, MTCT and infant feeding); providing on-going psychological and emotional support to HIV positive women as well as advice on disclosure; and facilitating access to community support groups, welfare grants etc.

- Efforts to provide 'couple HIV testing' as well as community-targeted interventions to address stigma, ignorance and prejudice, are important but relatively neglected components of the PMTCT programme that need to be strengthened.
- The option of using rapid saliva tests as an alternative to rapid blood tests should be explored as this could relieve some of the workload on professional staff.
- In view of the recognized clinical efficacy of NVP, operational research is required to determine whether the NVP that is dispensed is taken correctly; whether midwives and doctors pro-actively ask women in labour about their HIV status and self-administration of NVP; and whether labour wards are able to provide adequate patient confidentiality regarding HIV status.
- Some lack of clarity about the clinical and obstetric management of HIV positive women in labour needs to be addressed.
- Guidelines on post-partum care need to be modified as they are currently unrealistic. Sites should develop their own targets and guidelines that are context-based and feasible.
- Patient-held records are essential for adequate continuity of care. The need to protect patient confidentiality about HIV status needs to be balanced against the need to promote continuity of care and the desire to encourage a greater openness about HIV status.

## **EXPANDING THE PMTCT PROGRAMME**

There are no good reasons for delaying a phased expansion of PMTCT services in all provinces. The pilot sites have already generated a lot of useful and important lessons that can now be put to use.

The systemic weaknesses and infra-structural constraints identified by this evaluation are not reasons for delaying action, but are important for informing the planning and expansion of PMTCT services.

Plans for expansion must therefore simultaneously address the systemic and infra-structural constraints in order to avoid a multiplication of poor and/or non-sustained service delivery, as well as to reduce levels of health care inequity. As with other services, the full potential of the PMTCT programme to reduce the number of HIV infected babies and improve overall health status will only be realized if the health system is capable of delivering the service optimally.

While it would be wrong for the systemic and infra-structural constraints to be used as reasons for non-expansion, reducing the challenge of implementing a country-wide PMTCT programme to the administration of NVP is misleading. The impression created

that implementing the PMTCT programme is as easy as dispensing aspirin, fails to convey the many genuine complexities that are outlined in this report.

It would be more useful to highlight the potential of the PMTCT programme to act as an engine or catalyst for the improvement of the health system and of primary health care services in general. This is described in Section 6.3 of this report. Failing to conceptualize the PMTCT programme in this broader and catalytic role could represent a missed opportunity for the country, or even worse, result in the PMTCT programme undermining other essential areas of PHC.

The temptation to adopt a rapid and vertical approach to expanding coverage across the country, particularly given the intense media and public pressure, should be resisted. A more measured and phased approach would ensure better sustainability and coverage; help strengthen the health care system as a whole; invigorate the broader HIV/AIDS programme; and raise the general standard of maternal and child health care. However, it is contingent upon government to develop a coherent, transparent and credible plan.

However, while a phased and systematic expansion of comprehensive PMTCT services is being planned, NVP can and should be provided immediately to all pregnant women who are already known to be HIV positive, with appropriate counselling and information.

Given the differences in capacity and infra-structure, it would be reasonable for provinces to expand the provision of PMTCT services at different speeds. For provinces that are currently struggling with implementation in their two learning sites, a plan for expansion should include and begin with a strengthening of provincial management and support structures and the continued improvement of services in the learning sites.

With political and senior management commitment at both the national and provincial level, it should be possible for all provinces to begin implementing PMTCT services in some new sites by the middle of 2002.

A more appropriate budgeting formula will be required to ensure that historically under-resourced areas receive a more equitable share of funding and support, should there be an expansion of the programme. The 'gap' between existing resources and a minimum standard of health care infra-structure (especially in terms of human resources) should be measured in every sub-district across the country to help ensure that this gap is narrowed in the fullness of time.

Within provinces, the variation in health care infrastructure and other factors necessitates a more context-based approach to planning and implementation. Local conditions and problems require local solutions, and the formation of an effective "sub-district health system" offers the best organizational framework for the delivery of the PMTCT programme and of PHC in general.

## INFANT FEEDING AND CHILD HEALTH

With all the publicity surrounding government's position on NVP, the more important and serious issue of its policy on infant feeding and providing free formula has been neglected.

The current policy needs to be reconsidered, as there is a danger that it may do more harm than good in many communities. When one looks at overall child health as an outcome, instead of just HIV transmission, the benefits and advantages of promoting free formula become questionable. The downside of promoting formula feeding, and government subsidizing it are explained and discussed in section 6.2 of this report.

Although the long-term aim should be to enable all HIV positive women to provide safe and affordable *exclusive* formula feeding, under the current circumstances, the policy may lead to higher rates of mortality and morbidity due to other diseases, as well as higher rates of mixed feeding.

A national commission of experts should be urgently set up to review the current policy and guidelines on infant feeding and mother-to-child transmission.

One option that must receive serious and urgent attention is the post-natal administration of short-course anti-retroviral treatment to mothers and/or babies as a strategy for making breastfeeding safe.

Finally, the imperative to save babies from HIV should provoke a broader and urgent response from government and civil society to address child poverty, the unacceptable levels of child care and child mortality from easy-to-prevent causes.

# INTRODUCTION

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At the end of 2000, a decision was taken by the government of South Africa to implement a pilot programme for the prevention of mother-to-child transmission (PMTCT) of HIV. This resulted in two pilot sites being selected per province for the implementation of a PMTCT protocol developed by the national DoH. The pilot programme was largely funded by national conditional grants to each province.

An evaluation and research framework was developed, presented to MinMec and endorsed in July 2001. The Health Systems Trust was requested to help coordinate and implement this evaluation and research framework, where a particular emphasis was placed on ensuring that the lessons learnt from the implementation of PMTCT services be analysed and documented.


The areas of implementation that the research and evaluation was expected to cover, included assessing the provision of:

- voluntary HIV testing to pregnant women
- short course Nevirapine (NVP) to HIV positive pregnant women
- appropriate counselling and support for safe infant feeding practices
- follow-up care to mother-child pairs after delivery

This report does not provide any primary data on the impact of the PMTCT programme on HIV transmission or health outcomes in the 18 pilot sites (mainly because the programme is still too young and also because this will require the initiation of complex research studies). However, in view of the various policy debates surrounding this pilot programme, this report does discuss a number of policy issues related to the significance of PMTCT services within the wider context of the health care system, as well as HIV transmission and maternal and child health.

With both the experiences from the pilot sites as well as a review of health policy in relation to PMTCT, the report discusses and makes recommendations on the improvement of existing PMTCT services as well as on the establishment of an efficient, effective and sustainable PMTCT service across the whole country. Again, it tries to do this from the broader context of the health system as a whole.

The primary data and information for this report were based on numerous discussions and interviews with managers, coordinators and clinicians involved in the PMTCT programme. Site visits, document reviews, attendance of the national PMTCT Steering Committee meetings and some provincial PMTCT committee meetings have also



contributed. In order to ensure that the discussion on the broader policy issues are informed by a sound public health, clinical and scientific grounding, the international literature has been used.

A dossier of progress on PMTCT implementation for each province has been developed in an incremental fashion since September 2001, and a summary of some of this information is provided in Appendix 2.

Additional activities conducted by the Health Systems Trust have included working in close conjunction with the national DoH to establish a system of routine data collection, and to define a minimum set of data items and indicators for the national PMTCT programme. At the present moment there are still some shortcomings with the quality of routine data, and these are noted in the report.

Finally, a number of discrete research projects have also been commissioned and initiated by the Health Systems Trust in conjunction with the DoH and other agencies. The state of these research activities is described in Appendix 4.

## THE PROCESS AND PROGRESS OF IMPLEMENTATION

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The implementation of 18 PMTCT pilot sites is a complex process that has involved:

- The development of a PMTCT protocol which includes a set of clinical and patient care guidelines
- Financing and budgeting for, amongst other things, medicines, HIV testing kits, personnel and formula milk
- The selection of sites and their preparation
- The procurement of medicines, HIV testing kits and formula milk powder, as well as the establishment of appropriate supply, distribution and storage systems
- Training of clinical and management personnel across 9 provinces and 18 sites
- The creation of new posts at the provincial level to support the implementation of the programme
- The recruitment and deployment of lay counselors
- The development of a routine information and monitoring system

The national Directorate: HIV/AIDS, together with their provincial counterparts, have worked hard and tirelessly to initiate and implement the above actions smoothly and efficiently. Nonetheless, many constraints and difficulties have been experienced, some of which partly explain why many sites only began implementing the programme in the latter half of 2001. It is important to understand these constraints and difficulties within the broader context of the health care system:

- The fact that the health care system is still undergoing significant transformation, reorganization and structural change
- The difficulty of a national Directorate having to work with and through nine separate and different provincial DoHs of varying capacity
- Insufficient coordination and communication between the different units and divisions of the public health care system

- A rigid and inefficient bureaucratic environment that constrains the rapid implementation of new programmes
- The challenge of the national Directorate HIV/AIDS having to work under multiple, competing and urgent demands, many of which are made in a way that disrupts attempts to establish stable, effective and efficient management
- Sub-optimal management / technical capacity at the national level, as well as in many provinces, to implement a programme as complex as PMTCT within the difficult environment described above
- Understaffing and poor infra-structure of the health care system in many parts of the country
- Low morale and poor motivation amongst many front-line health care providers
- The continued denial and stigma about HIV/AIDS in the public as a whole

Some may dispute this description of the broader context within which the national PMTCT programme was implemented, or decry it as convenient excuses for the Directorate: HIV/AIDS. However, few would argue against the fact that the *general* organizational and management efficiency of the public health care system as a whole is a fundamental, underlying determinant of the success or otherwise of the national PMTCT programme. The quality and effectiveness of PMTCT services reflects the functioning of the health care system as a whole, and not just the dedicated management of the PMTCT programme within a single division of the public health care system.

Having said all of this, the fact that all 18 sites have implemented some degree of a comprehensive PMTCT service within the timespan described above, can be considered a positive achievement.

# 3

## OVERVIEW OF SITES

Province	Site	Start Date	Bookings per month	Antenatal HIV testing sites	Deliveries	F/up Care
<b>Gauteng</b>	<b>Natalspruit</b> Natalspruit hospital and J. Dumane CHC	May 2001	300	Hospital and CHC	Hospital and CHC	Hospital and CHC
	<b>Kalafong</b> Kalafong Hospital and Pretoria West MOU	June 2001	300	Hospital and clinic	Hospital	Hospital and clinic
<b>Western Cape</b>	<b>Guguletu</b> Guguletu MOU and 8 clinics in Nyanga district	Jan 2001	380	MOU	MOU and Mowbray Maternity Hospital	MOU and 8 clinics
	<b>Paarl</b> Paarl Hospital, T.C Newman CHC and 17 surrounding clinics	May 2001	270	Hospital and CHC	Hospital	Hospital, CHC and Clinics
<b>Northern Province</b>	<b>Mankweng</b> Mankweng Hospital and 19 clinics (many of which are small, isolated, under-resourced and understaffed)	Aug 2001	725	Hospital + Clinics	Hospital (few clinic deliveries; significant number of home deliveries)	Clinics and Hospital
	<b>Siloam</b> Siloam Hospital and 6 out of 17 clinics (some of which are small, isolated, under-resourced and understaffed).	Middle of Nov 2001	80	Hospital + Clinics	Hospital	Clinics and Hospital
<b>Mpumalanga</b>	<b>Shongwe</b> Shongwe Hospital and 9 out of 23 surrounding clinics	Sept 2001, but no VCT in clinics yet.	100	Hospital	Hospital	Hospital and Clinics
	<b>Evander</b> Evander Hospital, Lebohang CHC and Embalenthle clinic	October 2001	140	Hospital, CHC and clinic	Hospital, few deliveries at the clinic	Hospital, CHC and Clinic
<b>Free State</b>	<b>Virginia</b> Virginia Hospital and 8 clinics	July 2001	340	Hospital and clinics	Hospital	Hospital and Clinics
	<b>Frankfort</b> Frankfort Hospital and 8 clinics	August 2001	200	Hospital and clinics	Hospital	Hospital and Clinics

<b>KwaZulu- Natal</b>	<b>Durban</b> King Edward VIII Hospital and Kwamashu Polyclinic, Prince Mysheni Hospital and feeder clinics in section D and K, Umlazi	June 2001	1000	Hospitals, CHC and clinics	Hospitals and CHC	Hospitals, CHC and clinics
	<b>Pietermaritzburg</b> Grey's Hospital, Northdale Hospital and Sabantu and Northdale clinics, Edendale Hospital and Imbalenhle and Taylors Halt clinics, Church of Scotland Hospital	July 2001	725	Hospitals and clinics	Hospitals and clinics	Hospitals and Clinics
<b>Eastern Cape</b>	<b>East London Complex</b> Frere Hospital and 29 clinics, Cecilia Makiwane Hospital and 19 clinics.	July 2001	950	Hospitals and clinics	Hospitals	Hospitals and clinics
	<b>Umzimkulu Sub-district</b> Rietvei Hospital and 12 clinics (many of which are small, isolated, under-resourced and understaffed)	July 2001, but no VCT in clinics yet.	70	Rietvei Hospital	Rietvei Hospital (few clinic deliveries; several home deliveries)	Rietvei Hospital
<b>Northern Cape</b>	<b>Galashewe</b> Galashewe Day Hospital, Kimberley Hospital, Masakhane clinic and Roodepan clinic	August 2001	150	Day Hospital, Hospital and clinics	Day Hospital and hospital	Day Hospital, hospital and clinics
	<b>De Aar</b> De Aar Day Hospital, Motana clinic, Amalia clinic, Normzwakazi clinic and one CHC	August 2001	50	Day Hospital, clinics and CHC	Day Hospital	Day Hospital, CHC and clinics
<b>NorthWest</b>	<b>Thlabane</b> Rustenberg Hospital, Thlabane Health centre and 4 clinics	July 2001 (Rustenberg only started in Dec 2001)	100	CHC and clinics	CHC	CHC and clinics
	<b>Lehurutshe</b> Lehurutshe District Hospital and 21 surrounding clinics	July 2001	210	Hospital and clinics	Hospital	Hospital and clinics
<b>TOTAL</b>			<b>6090</b>			

# 4

## COVERAGE AND UPTAKE OF PMTCT SERVICES

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21 hospitals (4 tertiary, 8 regional and 9 district), 12 MOUs / CHCs / Day Hospitals / Poly-clinics, and about 160 clinics currently provide ante-natal counselling, rapid on-site HIV testing and the dispensing of NVP as part of the national PMTCT programme. Of these sites, the hospitals, the MOUs / CHCs / Day Hospitals / Poly-clinics and a few clinics provide intra-partum care.

The approximate number of bookings in total per month = 6,090. This comes to about 9% of the total number of countrywide bookings per month (based on the National Indicator for expected deliveries which is 820 781 for 2002). A full breakdown of these figures province by province is provided in Appendix 1.

The true figure for access in South Africa is, however, considerably more. The Western Cape has extended its coverage of PMTCT services to 30 sites, and Gauteng has initiated six additional PMTCT sites. In addition, a number of research sites have been providing a PMTCT service as part of their work – these include Baragwanath Hospital and its surrounding clinics in Soweto, and the Hlabisa health district in KZN. Finally, as reported in the newspapers recently, many hospitals and doctors across the country are prescribing NVP to pregnant women known to be HIV positive.

By adding in these sites, a rough estimate of the proportion of pregnant women in this country with access to HIV counselling, testing and NVP is 12-15%.

The numbers of women who agree to be tested, however, are considerably less. Approximately 51% of pregnant women in the national PMTCT sites have agreed to an HIV test. This translates to a figure of 3133 /month. There is however significant variation between the provinces, as well as between the different sites (see Appendix 1).

The province with the highest testing uptake rate is the Western Cape, which has been operating for the longest length of time, followed by Kwazulu-Natal. In the Eastern Cape, the testing uptake rate in East London is only 28%, whilst the rate in the under resourced rural site in the Umzimkulu site is 90%. The provinces with the poorest rates are Mpumalanga and the Northern Province. The rates for the two sites in Mpumalanga are 19% in Shongwe and 22% in Evander, and reflect the inability of staff to cope with the patient load due to the lack of lay counselors. In the Northern Province the rate in Mankweng is 18% and in Siloam it is 17%. It is important to note

that these two provinces were among the last to commence PMTCT services, and that there is a natural tendency in all sites for the initial months of a PMTCT service to have low HIV testing uptake rates. Other reasons for differences in the uptake of VCT are discussed later.

A nationally defined target for the uptake of HIV testing amongst pregnant women has not been established. However, as a rule of thumb, any site managing an HIV testing rate of > 80% can be considered to be doing 'very well' (a testing rate of > 95% would be unrealistic, and would suggest possible 'coercion', as opposed to 'encouragement'). Sites with a testing rate between 60%-80% can be classified as doing 'reasonably well', while those below 60% need to be targeted for extra support. Based on the available *cumulative* statistics, the success of VCT uptake is as such:

<b>HIV testing rate</b>	<b>Sites</b>
<b>&gt; 80%</b>	Umzimkulu, Durban, Paarl, Guguletu, De Aar
<b>60 - 80%</b>	Natalspruit, Pietermaritzburg
<b>&lt; 60%</b>	Kalafong, Shongwe, Evander, Virginia, Frankfort, East London, Kimberley, Thlabane, Lehurutshe, Mankweng, Siloam

Of the women agreeing to HIV testing, 30% have been HIV+, which is higher than the national HIV prevalence of women attending ante-natal clinics of about 22%. Table 1 shows the variation between provinces and how the HIV positive rate in the PMTCT sites compare with their provincial average. The reasons why PMTCT sero-positivity is usually higher than the underlying provincial HIV prevalence are:

- > a testing bias towards pregnant women with signs, symptoms or a history suggestive of HIV infection
- > women who know or suspect they are HIV positive may be coming to the national sites from outside
- > the national PMTCT site might have a higher true prevalence rate than the province as a whole

In the very few sites where the PMTCT sero-positivity rate is lower than the underlying provincial ante-natal HIV prevalence, the likely reasons are that the site prevalence is actually less than the provincial average, or that women who suspect themselves to be HIV positive may avoid seeking care in the PMTCT sites.

**Table 1**

Province	Site	PMTCT sero-positivity rate	HIV prevalence (2000 ante-natal HIV surveillance)
Gauteng	Natalspruit	33%	29.4%
	Kalafong	43%	
Western Cape	Guguletu	21%	8.7%
	Paarl	8%	
Northern Province	Mankweng	17%	13.2%
	Siloam	0%	
Mpumalanga	Shongwe	47%	29.7%
	Evander	39%	
Free State	Virginia	32%	27.9%
	Frankfort	23%	
KwaZulu Natal	Durban	44%	36.2%
	Pietermaritzburg	34%	
Eastern Cape	East London Complex	25%	20.2%
	Umzimkulu Sub-district	35%	
Northern Cape	Galashewe	32%	11.2%
	De Aar	5%	
NorthWest	Thlabane	42%	22.9%
	Lehurutshe	17%	

On the basis of these VCT uptake and sero-positivity rates, a total of 6343 HIV+ pregnant women have had the chance of being administered NVP in the national PMTCT sites (see Appendix 1 for provincial breakdown). However, the recorded number of HIV+ women who have delivered with the correct administration of NVP to both mother and baby is only 1,932 (figure excludes data from Gauteng which is not available). The reasons for this large difference in numbers are:

- Firstly, because HIV testing typically occurs several months before delivery, at any given point in time, the cumulative number of identified HIV + pregnant women will be more than the cumulative number of deliveries (especially at the beginning of a programme).
- Secondly, it is possible that women accessing the PMTCT service ante-natally may deliver elsewhere.
- Thirdly, there may be an under-recording of figures in the labour wards.
- Finally, some HIV positive women may go to another clinic for a second HIV test in the hope that the second test will be negative – while women can be tested for HIV more than once, they can only deliver once!

# IMPLEMENTING THE PMTCT PROGRAMME - LESSONS LEARNT

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This section focuses on different aspects of the PMTCT programme in order to draw out the key findings, lessons and experiences that may assist in strengthening the current programme, and informing a possible expansion of PMTCT services to other sites.

## 5.1 Uptake of HIV testing amongst pregnant women

There are three broad sets of factors determining the HIV testing rate. These are:

- The availability and accessibility of counselling and testing facilities
- The quality of encouragement and counselling
- Community factors

### The availability and accessibility of counselling and testing facilities

#### Human resources

HIV counselling and testing is a difficult and time-consuming procedure. Suggested *minimum* standards for counselling as part of a PMTCT service include the need to provide an average of 60 minutes of initial pre- and post-test counselling, together with two further ante-natal counselling sessions of an average of 30 minutes each. There is no way in which existing staff, with other clinical and public health duties, can cope with such an increase in workload.

For example, some of the clinics surrounding Shongwe Hospital in Mpumalanga have to provide a comprehensive PHC service with only 2 – 4 nurses. In another rural clinic, the unavailability of lay counselors and the shortage of staff, meant that there was only one nurse available to do all the education, counselling and testing, resulting in long waiting times, and consequently, a poor uptake rate.

As a consequence the employment of 'lay counselors' to support health workers is a cornerstone of the PMTCT programme. However, some provinces (Northern Province

and Mpumalanga) have not yet established a system for the recruitment, management and remuneration of lay counselors, and in other sites, there are still not enough lay counselors to provide a quality PMTCT service.

Table D in Appendix 2 describes how provinces have recruited, deployed and remunerated 'lay counselors' using different approaches. Some difference in the way provinces organize the availability of a cadre of 'lay counselors' is appropriate. However, the remuneration rates of lay counselors range from zero to R2,800 per month, and this magnitude of difference between provinces may be inappropriate.

In many provinces the recruitment of lay PMTCT counselors occurs in an unclear and uncoordinated policy environment for lay health volunteers / workers in general. As a consequence, lay PMTCT counselors, home based carers, VCT counselors, DOTS supervisors and "traditional" community health workers are being paid differently. This inconsistency has led to charges of unfairness and a general unhappiness of those lay health workers who are on the lower end of the remuneration scale. On the other hand, those provinces that have stated a desire to adopt a uniform and coordinated system, have effectively delayed the recruitment and deployment of paid lay PMTCT counsellors.

Some provinces have also cited bureaucratic, administrative and labour relations difficulties with the recruitment and remuneration of lay workers, and are therefore employing a strategy of funding NGOs to recruit, manage and remunerate lay workers.

While insufficient lay counselling capacity has been a significant rate-limiting step to the uptake of HIV testing and the improved quality of counselling, the provision of HIV counselling services cannot be left as the sole responsibility of 'lay counselors'. At one of the national PMTCT Steering Committee meetings, the need to discourage professional health workers from thinking that they can abdicate their counselling and education responsibilities to lay counsellors was discussed. In any case, in some sites, clients have simply refused to be counseled (or even informed about HIV and MTCT) by a lay worker, and have demanded to be informed and counseled by a trained health worker. As one site coordinator said, "in our area we have the educated intellectuals – they will not see a lay counselor – they refuse".

Lay counselors are currently barred from performing the rapid on-site HIV diagnostic test, which is estimated to take an average time of 30 minutes per client, placing this burden squarely on the shoulders of nurses.<sup>1</sup> One province is planning to adopt the use of a rapid saliva test which can be conducted by lay counselors, and which could therefore free up nursing staff from the activity.

Therefore, in spite of the recruitment of 'lay counselors', the HIV testing component of the PMTCT programme constitutes a considerable increase in workload for ante-natal professional health workers. Those facilities that were already under-staffed, are struggling to provide a good service without compromising other services. While it is possible that time may be created through efficiency gains, there are concerns that the increase in workload (without additional staff) may result in a deterioration of the quality of care elsewhere, and to stress and burn-out amongst some staff.

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1 In some facilities, lay counselors are performing the on-site site testing despite the regulation barring them.

Another human resource problem has been 'staff rotation' policies that have led to a high turn-over of staff. As a consequence many provincial HIV units have had to constantly reorganize and reschedule new training interventions for health workers operating in the PMTCT facilities, a problem that seems to cut across and affect other health services.

Even without the rotation of staff, in most sites, organizing and providing appropriate training to all nurses is an unfinished challenge. For example in one of the larger urban sites with more than twenty PHC facilities, despite the involvement of local universities and NGOs, and despite a heavy emphasis on training, only 75% of all professional nurses had received formal training in PMTCT and HIV counselling by the end of 2001, and no staff nurses or enrolled nurses had been trained yet.

Part of the reason why the training of staff is such a big challenge is because the base knowledge and counselling skills of staff is poor, resulting in the need for intensive training interventions spread over several days, rather than shorter training interventions that can reach a larger number of staff in a given time. This knowledge and skills base is known to vary across different parts of the country, and is a reflection of the varied quality of training institutions and their students. An important strategy that must therefore be implemented straight away is to ensure that HIV counselling and PMTCT are taught thoroughly and effectively in all under-graduate health sciences training institutions.

### **Medical input and support**

Sites have had varied experiences with the role and involvement of doctors. The benefit of doctors being a visible and pro-active part of the PMTCT programme has been described in a number of sites. On the other side of the coin, sites with a lack of interest and support from doctors have experienced problems.

In some sites such as Durban, Pietermaritzburg, Rietvlei and East London, senior doctors play a leading and catalytic role. In other sites, doctors do not appear to be significant, especially in the ante-natal period. This is partly because doctors generally play a limited role in ante-natal care (except for high-risk pregnancies), and because traditionally, counselling and patient education has not been considered part of the medical role in the public sector. However, there has been a feeling in several sites that doctors have not played a clinical leadership role, are uninterested or, "have been left out of the training on PMTCT".

It appears that while doctors are not always central to the provision of direct patient care, they are central to a well-functioning obstetric service and have an important clinical leadership, quality control and training role, which supports and sustains the programme.

### **Physical space**

Another significant challenge of all 18 sites has been overcoming the lack of physical space and furniture to provide counselling in a comfortable and private manner. In the larger facilities (e.g. academic, regional and even district hospitals), it has usually been possible to identify spare rooms that can be used for the dedicated purpose of pre- and post-test counselling.

However, many clinics have had to resort to counselling in inappropriate places (e.g. outside in a car, in the clinic kitchen or in a room with no privacy), whilst waiting for longer-term solutions. Purchasing pre-fabricated huts or containers as makeshift consulting rooms and building partitions to create more rooms, are some of the solutions pursued by provinces. One site has gone to the lengths of renovating, painting and refurbishing an existing building to create dedicated HIV counselling rooms which are private, comfortable, spacious and of a first-world standard.

The difference in the comfort and privacy of counselling facilities in the different sites is a stark reminder of the vast inequities that exist within the public health sector. In some facilities, the lack of space means that two nurses may have to share the same room and consult patients from opposite ends of the same table.

### **Testing kits**

The availability of testing kits does not appear to have been a problem in any of the sites. Although a formal, external evaluation of the use of rapid testing kits has not been conducted, there have been no indications of any problems with the reliability of the rapid HIV test results.

### **The arrangement of space, patient flow and waiting times**

The need to provide room and time for PMTCT services is a challenge to the organisation of space, patient flow and time management in many facilities. Space and time needs to be found for individual counselling, group information and education sessions, obstetric examinations, the handling of blood specimens, child follow-up consultations and the secure storage of formula milk powder.

In terms of ante-natal care, the organisation of dedicated days or times in the week for ante-natal care (especially for the first ante-natal booking service) has been found to be a time-saving strategy that also allows pregnant women to meet each other as a group. However, this has resulted in an uneven spread of HIV testing and counselling needs across the week. On these “ante-natal booking days”, the volume of required counselling and testing may simply out-strip the number of counselors and space available. Many clients refuse to wait in a queue and decline to be tested or counseled as a result.

In order to make testing and counselling more accessible, it may be necessary to spread out the ante-natal care workload across the week, and abandon the practice of concentrating ante-natal patients in one or two days of the week. Doing this, however, will result in losing certain advantages such as the efficiency of collecting blood specimens in one go, and providing group health education to pregnant women. In some clinics blood specimens for ante-natal booking are only collected once a week (due to a lack of transport), and in such situations, changing this arrangement would not be feasible or desirable.

In some of the larger facilities which have been able to provide dedicated space and rooms for HIV counselling and testing, a problem that has cropped up is the lack of anonymity of the rooms which easily become associated with HIV testing. In some sites, there are even signs pointing to HIV testing rooms, which is likely to act as a deterrent to patients.

## The quality of encouragement and counselling

Unlike with 'standard' VCT services that wait passively for clients to request HIV counselling and testing, a PMTCT programme requires a more pro-active approach whereby *all* pregnant women are actively counseled about the benefits of HIV testing.

This includes providing all pregnant women and community members with information about the benefits of testing in pregnancy. A general approach has been to offer information and education to groups of clients, after which individuals are invited to go for individual counselling and HIV testing if they agree. However, there seems to be room for improving other sources of information on PMTCT such as leaflets and posters in the local language. One notable exception is a series of patient leaflets designed by the Free State DoH.

Facilities where morale and motivation is low, or where there is a denial towards HIV amongst staff, may not provide adequate encouragement for pregnant women to choose to test. The morale, motivation and attitudes of staff toward HIV are therefore important factors that need to be optimized to improve uptake rates and the quality of counselling.

Provinces have embarked upon different strategies for the provision of training, relying significantly on NGOs such as PPASA, Lifeline and university departments. Many ATICCs have also been brought in to help provide training.

To date there has been little formal evaluation of the quality and effectiveness of the training. Preliminary research conducted in the national VCT sites and in some PMTCT sites indicates that some of the training that has been provided is not culturally appropriate; provides theoretical information at the expense of improving skills and practice; and does not adequately deal with the attitudes, prejudices and denial of the trainees themselves. A further weakness is the lack of on-going in-service training and support for staff and lay counselors working in the programme.

A pointer to the current inadequacy of counselling and testing are reports that few pregnant women disclose their status to their partner or families. This reflects inadequate attention paid to empowering the client to disclose their HIV positive status, a lack of effort or capacity to provide 'couple counselling and testing' as well as the degree of stigma, ignorance and prejudice in the community.

Many sites have also noted the importance and benefit of local PWA support groups for clients who have tested positive. Where they exist, they provide an invaluable source of support to HIV positive pregnant women. Where they do not exist, efforts must be made to establish them.

The burn-out of staff providing HIV testing services on a regular basis has been recognized in all sites. Providing supportive supervision to counselors, arranging peer support groups, and in a few places, formal de-briefing sessions with trained psychologists or social workers are some of the efforts being made to help staff cope with the emotional and psychological stress of conducting HIV tests. These efforts are important for the quality and sustainability of HIV testing services and require strengthening.

Language is another factor that influences the quality and accessibility of counselling. For sites that cater for clients from a mix of language groups, there have been reports

of occasions when a counselor with the appropriate language was not available. Other characteristics of counselors such as their age and gender have also been noted as potential factors that influence the uptake and accessibility of counselling services.

### **Community factors**

The extent of denial and stigma in the community impacts on the uptake of HIV testing, the disclosure of HIV test results to sexual partners and families, and on desired changes in behaviour after testing. Many of the sites have commented that community education and mobilization is an important, but relatively neglected aspect of the PMTCT programme to maximize coverage of women, promote couple testing and disclosure as well as setting up PWA support groups. Some provinces and sites have organized community meetings and IEC campaigns that have used local radio, print media and local advertisements which seems to have helped overcome stigma, denial, prejudice and ignorance.

## **5.2 The administration of NVP to mothers**

The national PMTCT protocol stipulates that pregnant women who are 28 weeks or more in their gestation be given a tablet of NVP for self-administration in the event of going into labour. Women are asked to self-administer NVP because the earlier it is taken during active labour, the more effective it will be. Should the mother's dose of NVP be taken within two hours of delivery, the baby should be given an extra dose of NVP immediately after delivery (with a 'normal' dose between 24 and 72 hours after delivery). Should a mother take NVP without going into 'active labour', she should be dispensed with a second NVP tablet. All midwives, nurses and doctors working in labour wards are expected to enquire and ensure that all HIV positive women in labour have correctly self-administered their NVP tablet, and if not, to administer NVP in the labour ward.

Although this evaluation was not designed to review the clinical efficacy of NVP, its side-effects or the potential for creating resistance, Appendix 5 provides a summary of the latest international scientific consensus on the latter two issues. There are, however, a number of operational issues related to the administration of NVP that are important to evaluate.

### **The self-administration of NVP**

At the present moment research has not been conducted to formally assess the treatment literacy of patients or the correctness of NVP self-administration. Many sites however report a high number of women who require NVP to be dispensed in the labour ward, which suggests that tablets are not correctly self-administered or are lost; or that women forget to take the tablet when they go into labour.

A possible concern about the self-administration of NVP is that NVP tablets may be marketed and sold as a cure for HIV/AIDS. However, this has not been reported in any of the sites and is unlikely if women have been appropriately counseled. In any case, women are only dispensed one tablet at a time.

### **Multiple dispensing**

Some women require multiple doses of NVP because they may take the tablet when not in active labour. It is not known how many women take multiple doses of NVP during a single pregnancy. Neither is the effect of this in terms of creating NVP resistance known.

### **Active enquiry about the correct self-administration of NVP in the labour ward**

The failure to make proper enquiries during labour about the correct self-administration of NVP could effectively amount to a “missed opportunity” to prevent vertical transmission.

It is possible that in the busy environment of a labour ward, especially one that is under-staffed, staff may not ask pregnant HIV women if they have taken their NVP. The attitude and knowledge of staff about the PMTCT programme are also important factors. Staff who have no interest in the PMTCT programme or who are reluctant to deal with HIV/AIDS, may not want to identify women who are HIV positive.

On the other hand, pregnant women may not be in a psychological or emotional state to correctly recall if they took their NVP tablet correctly. Of greater concern is the fact that HIV positive women in labour may not be readily identifiable because of their reluctance to reveal their HIV status in delivery rooms that lack privacy, or to staff who have not been involved in their ante-natal counselling and care. The poor state of some labour wards where patient privacy may only amount to a flimsy curtain between beds is a barrier to adequate care during labour in general, but especially for women who are HIV positive.

A formal evaluation of these aspects of the PMTCT programme has not yet been made. However, anecdotal reports suggest that “missed opportunities” are not a big problem. In a number of sites, the considerable amount of NVP dispensed within health facilities suggests that staff are pro-actively asking women whether they have taken NVP. On the other hand, the discrepancy between the numbers of HIV positive women diagnosed in the ante-natal period and the number of HIV positive deliveries might suggest that some HIV positive women are not being identified in labour, or that because of the busy nature of labour wards, NVP is being dispensed without being recorded.

## **5.3 Obstetric practices**

In addition to the administration of NVP, there are a number of obstetric interventions that must be practiced for the correct and safe care of HIV positive women in labour. To start with, there should be strict adherence to all the precautions and safety procedures for the protection of staff from occupational exposure. These precautions and safety procedures should furthermore be applied universally to all women regardless of their known HIV status.

Secondly, there are certain obstetric practices that can minimise the risk of vertical transmission of HIV. These include avoiding the artificial rupture of membranes, minimizing the duration of ruptured membranes, minimizing the duration of active labour (especially in the second stage) and avoiding instrumental or assisted vaginal

deliveries. Although performing elective caesarian sections reduces the rate of transmission, this is not part of the current PMTCT protocol due to the unfeasibility of this option.

The correct implementation of the practices described above will depend on the general staffing levels, expertise, experience and capacity of doctors and midwives within the sites. Although there has not yet been an in-depth review of clinical obstetric practice in the PMTCT sites, the sub-optimal staffing levels and certain indicators of the quality of care in some facilities suggests that the general standard of obstetric care is inadequate.

Finally, in one site, obstetric staff indicated that there was no difference in clinical practice or clinical protocols for known HIV positive women, because of the practice of taking universal precautions. In other words, all pregnant women in labour were managed as though they were potentially HIV positive. In other sites, however, there was an understanding that obstetric practice was different for women known to be HIV positive. This reveals a lack of clarity around the clinical guidelines for the care of HIV positive women in labour.

## **5.4 The paediatric administration of NVP**

The national PMTCT protocol stipulates that the babies of all HIV positive mothers receive a dose of NVP suspension between 24 and 72 hours after delivery. If the mother only received her dose of NVP within 2 hours of delivery, the baby should actually receive two doses of NVP.

Several facilities have cited some difficulties with the administration of NVP due to the fact that many women are discharged home before 24 hours have elapsed after delivery. As a consequence some sites are dispensing the dose of NVP suspension 12 hours after delivery. Pharmacokinetic studies conducted at the University of Natal have suggested that this should be as efficacious as waiting 24 hours after delivery.

Immediately after birth, there are three places that a baby is likely to be taken to: the post-natal ward with the mother; the nursery (without the mother), or the special / intensive care unit. In order to make sure that all eligible babies receive the right dose of NVP at the right time, it is important that some continuity of care is established between the labour ward and the post-natal ward, nursery and special care unit. The extent to which drug charts and patient case notes clearly indicate to post-natal nursing staff which newborns must receive NVP before discharge or within 72 hours of delivery needs to be evaluated.

## **5.5 Post-delivery follow-up and continuity of care**

The national PMTCT protocol makes it clear that care must extend beyond the point of delivery for both mother and child. All women are recommended to go for a post-natal check-up 3-14 days after discharge, and further visits are recommended every two weeks in the first month and once a month thereafter. These visits should provide medical care as required, permit access to free formula, as well as provide on-going clinical care and support for infant feeding.

Infants of HIV positive women are recommended to be followed-up weekly during the 1<sup>st</sup> month of life, and monthly thereafter, until the age of 12 months. After that they should be monitored 3 monthly until they are two years of age, unless the child is ill. In addition, co-trimoxazole prophylaxis is to be provided from 6 weeks of age. At 12 months, an HIV test will be conducted. If this is negative, cotrimoxazole prophylaxis will be stopped. For children who are HIV-positive, cotrimoxazole will be stopped if they are well and growing. If the infant has had pneumocystis infection, more than two episodes of pneumonia, an AIDS defining illness or is not growing well, cotrimoxazole will be continued for life.

There is currently little information on the uptake, frequency and regularity of follow-up visits. Many sites however have recognized that providing on-going care to mothers and children is a formidable challenge. The challenges to providing follow-up care are numerous, and include:

- Poor access to health facilities due to long distances and a lack of affordable transport
- Poor patient records which make it difficult to maintain a continuity of care
- Long waiting times and queues
- Patient mobility in and out of the sites

In some sites, free formula is only made available at the delivery facility. For women who live far from the hospital or MOU, the lack of availability of free formula at a nearby clinic can make it expensive and difficult for her to get her formula.

Difficulties with follow-up and continuity of care tend to be more acute in sites where there is poor communication between ante-natal services, hospitals and clinics, where patient mobility is high and where there has been a relative over-emphasis on the obstetric aspect of the PMTCT programme in relation to out-patient child health and medical services.

Although there are massive infra-structural barriers to the full implementation of the follow-up guidelines of the national PMTCT protocol, the Paarl site in the Western Cape (a well resourced and low prevalence site) offers an example of excellent care. During the ante-natal period, mothers are counselled and advised to choose a clinic for their follow-up. Sometimes mothers will choose a clinic distant from their homes in order to protect their confidentiality. The PMTCT site manager will then take the mother to the clinic to introduce her to the clinic staff. A special register allows for these patients to be followed up over time. This arrangement would be impossible in many of the rural sites.

Anecdotal reports of the patient-held cards of HIV positive women being lost or defaced to protect their confidentiality indicates that some women do not want to disclose their HIV status after delivery. In order to get around this problem, health workers have been devising all manner of coded terms and markers of HIV positivity that will be recognized by health workers, but not by members of the general public. There have been concerns that such actions to protect patient confidentiality may re-inforce stigma and silence, as well as undermine the continuity of patient care across different service providers.

## 5.6 Organisation and management

Experience from all the sites has pointed to the fundamental importance of leadership and effective management as key ingredients of successful PMTCT sites. This is unsurprising given the fact that the programme requires the recruitment of new staff (PMTCT coordinators and lay counselors), the creation of physical space for counselling, the training of staff in HIV, MTCT and infant feeding, the establishment of linkages and referral systems between different parts of the health care system, community mobilization and the regular supply of medicines, testing kits and formula.

### Provincial leadership and management

Sites with the involvement of the highest levels of provincial government have been most successful in implementing the PMTCT programme. The role of senior managers is important in integrating the programme horizontally, sharing the workload across a number of departmental units and avoiding the trap of locating the programme within a narrow and vertical management system. The establishment of functional multi-unit steering committees appears to have worked well in getting the provincial department as a whole to pull together. Senior managers are also required to play more of a strategic role in balancing the requirements of the PMTCT programme with the requirements of other HIV and PHC services.

The presence of a dedicated 'driver' at the provincial level is critical. However the skills and qualities of such a person are important. The driver needs to have not only the technical proficiency to understand the clinical and public health aspects of the programme, but also the seniority and authority to make and implement the required decisions. Alternatively s/he needs to work with other people at the provincial level with the required skills and competencies.

In some provinces however, conflict around turf and a lack of clarity about roles and responsibilities has weakened provincial capacity to implement the programme.

An important ingredient has been the availability of a local pool of PMTCT 'experts' and clinicians who can be drawn upon to provide training and support. The Western Cape for example has had the benefit of academics and consultants from the University of Cape Town, in addition to local NGOs to support their sites. In Gauteng and Durban, expertise located in Baragwanath and King Edward Hospital have been able to provide support. In other provinces however, there is still a need to increase the training capacity required to continuously improve the quality of services, and will be essential should there be an expansion of services to other sites.

Provincial PMTCT coordinators also need to have the authority and technical legitimacy to work with and through the different role-players at the site level.

The creation of a CCLO post has been useful for most provinces, although some provinces have taken a long time to appoint people to the posts. Concerns about the short-term contractual nature of the post and its relative lack of seniority have been expressed. In some provinces too much responsibility has been placed on the shoulders of the CCLO. Provinces whose Directors of PHC and Directors of HIV and MCWH have taken active leadership roles, with the CCLO operating under their supervision, have shown quicker and more effective implementation.

## Site preparation and management

The careful preparation of sites prior to implementation appears to be an ingredient of success. Ideal site preparation starts with careful planning, staff training and orientation, the recruitment of lay counsellors (preferably done with and through a credible NGO), the training of lay counselors, community mobilization and the establishment of adequate physical space and privacy.

A PMTCT service requires leadership and good coordination within the site. Actions at the community level, counselling and testing in ante-natal clinics, delivery care and NVP administration in labour wards, and post-natal care in clinics must ideally form part of a seamless continuum.

Those PMTCT “sites” that were identified as a network consisting of a hospital and its feeder CHCs / clinics were better suited to deliver a comprehensive PMTCT service than those sites that essentially consisted of single, isolated facilities. Provinces that establish viable health sub-districts (in line with the WHO District Health System model) with sub-district health management teams will have the best chance of expanding PMTCT services.

A good functional relationship between clinics, PHC programmes and hospitals is important. The Thlabane site in the North West struggled to implement the PMTCT programme for a long time because of the non-participation of Rustenberg Hospital. In Gauteng, the focus on hospitals and relative neglect of their links to clinics has caused weaknesses and problems.

## Training and Human Resource Development

The effective organisation and provision of training is possibly the most important function of national and provincial management. Unless the available human resources at site and facility level have the correct and appropriate knowledge, skills and attitudes, the PMTCT programme is only partially effective.

Although there has been a tremendous amount of training in the PMTCT sites, human resource development remains a key challenge (Appendix 2, Section B describes some of these activities province by province). Some of the findings include:

- Provinces with ready and easy access to academic and technical experts are at a distinct advantage over those that don't.
- The tendency for provinces to manage and organize their own training interventions is an appropriate delegation of responsibility from the national office. However, some provinces require the national office to facilitate support from non-government agencies and academic / tertiary institutions (e.g. from some of the better resourced provinces).
- In spite of training, some nurses and counselors have difficulties with aspects of HIV counselling, and correctly advising women about infant feeding, and suggests the need to evaluate and strengthen existing training interventions.
- In terms of the content of training, the focus to date has been on HIV counselling and testing and on vertical transmission. There is a need to balance this with more training on infant feeding and child health.

- Off-site, formal classroom-based training (usually for the development of knowledge and understanding) needs to be complimented with more on-site in-service training with a focus on skills development and problem solving
- Doctors are inadequately targeted for training in some sites, nor are they being fully used as trainers of other staff.
- The balance between providing in-depth quality training versus rapid training to achieve a faster coverage of staff needs to be weighed up carefully on a site by site basis. The baseline capacities for staff to develop new knowledge and skills varies across the country, and ideally training would be tailored accordingly.
- Some provinces have taken the initiative to engage with nurse training institutions so as to develop under-graduate curricula that covers PMTCT.

### **Supply and distribution of consumables and equipment**

In general, there have been few problems with the supply and distribution of NVP, testing kits and formula. Although there were delays with the transfer of the conditional grant, provinces made other arrangements to purchase the supplies and equipment required so that they could start-up their sites quickly. For example, in the Northern Province, the provincial pharmacy budget was used. In Mpumalanga, due to the delay in transferring national funds, initial supplies were provided from Gauteng. Many provinces also drew on their provincial VCT programmes, especially for making available rapid testing kits and for providing training.


### **Budgets and Funding**

The conditional grant allocated from the national government to the provinces was held up for a considerable length of time due to administrative blockages. Funding did not actually reach the provinces until September / October 2001. In order to move ahead with the implementation of PMTCT services, provincial funds were used during the initial phases of development. However, the implementation of PMTCT services was delayed in provinces without ready access to other sources of funding.

The provincial PMTCT budgets from the national grant were calculated on the basis of HIV prevalence and the number of deliveries expected. Management capacity, rurality, the level of health care infra-structure and staffing levels were not adequately factored into the apportioning of budgets to the provinces. Money was not available in the national grant to upgrade facilities, and provincial budgets had to be used for this.

### **Routine monitoring and health information systems**

All 18 national sites are currently providing some data on a routine basis. Front line providers are responsible for collecting data which is sent to PMTCT site coordinators and / or provincial PMTCT coordinators on a weekly basis. However, much of the quality and reliability of this data is poor. Not all provinces used the same data definitions or calculated indicators using the same numerator and denominator. (See notes in Appendix 1).



A nationally defined data set with clearly defined indicators was only finalized in December 2001. Consultants have now been funded by the national DoH to provide support and training to each of the provinces and the 18 sites to ensure good quality and standardised routine data collection.

# 6

## IMPACT OF THE NATIONAL PMTCT PROGRAMME

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While an evaluation of the process of implementation is important for identifying lessons that can help improve efficiency, effectiveness and sustainability, it is also useful to have some idea of the impact of the programme on improving health status.

The PMTCT programme should be evaluated on the basis of two primary goals. The first is in terms of reducing the rate and overall numbers of HIV transmission from mother to child. The second, and perhaps more importantly, is in terms of its contribution to improving the health status of children and mothers, whether HIV positive or HIV negative.

Relevant indicators of the first goal include the vertical transmission rate, and the numbers and relative proportion of HIV positive pregnancies. The vertical transmission rate will be reduced by the effectiveness of implementing the national PMTCT protocol. The numbers and relative proportion of HIV positive pregnancies, on the other hand, will be reduced by the effectiveness of HIV prevention and family planning strategies. These latter two strategies seem to have been inadequately highlighted in current debates about MTCT.

As far as improving overall child health is concerned, whilst preventing HIV transmission to children is clearly an important intervention, other interventions that will also have a big impact include:

- Addressing child malnutrition and poverty
- Improving immunisation coverage rates and the quality of primary level child health clinical care
- Improving the care of children at home
- Improving maternal health outcomes and female literacy rates

These interventions are mentioned in order to stress the point that PMTCT services are but one of several interventions required to attain acceptable standards of child and maternal health in the country. Children who are saved from HIV but who die from malnutrition and other preventable causes reduces the full benefit of the PMTCT programme.

Measuring the impact of the PMTCT programme is difficult and methodologically complex. Quantifying vertical transmission rates is complicated by the difficulties of following up children so that their long-term outcomes can be recorded. In addition, determining the HIV status of children is complicated by the presence of maternal antibodies and by the fact that testing for viral DNA/RNA is expensive. The challenges of measuring the impact of PMTCT services on overall child health are even greater, and would require a significant amount of funding and research management capacity. A group of epidemiologists, scientists and statisticians are being convened to discuss the worthwhile, affordable and feasible options to measure the impact of PMTCT services, and to report their recommendations to the national DoH in due course.

However, it is possible to make some inferences about vertical transmission rates based on knowledge and information that has been generated from various other studies.

## 6.1 Vertical Transmission Rates

The diagram on page 28 explains how a PMTCT programme might impact on vertical transmission rates. It is based on a consideration of what might happen to 100 HIV Positive pregnant women under different situations.<sup>2</sup>

The first column on the left of the diagram describes what would typically happen to 100 HIV positive pregnant women *with no PMTCT intervention*, and where infant feeding practices continue unchanged. Although there has been limited research on infant feeding practices, it is known that most women provide breastmilk with other foods within the first few months of life and that many of those women who initiate breastfeeding often continue to do so for up to a year, or even longer. The second column describes what would typically happen to 100 HIV positive pregnant women *who receive the NVP protocol*, but where infant feeding practices continue unchanged. The third column describes what would happen to 100 HIV positive pregnant women *who receive the NVP protocol and provide exclusive formula feeding*.

### *Transmission rates before delivery*

Before delivery, about 7 out of 100 women will infect their children with HIV. On an individual basis, the risk is greatest in women who have a high viral load, or who have an infection of the internal lining of the uterus (chorio-amnionitis). Anti-retroviral medication taken by women could reduce the risk of transmission to almost zero given proper compliance.

### *During labour and delivery*

During labour and delivery, approximately 16 more babies will become infected, if no PMTCT interventions take place (first column). In other words, 16 out of 100 HIV positive pregnant women will infect their children during labour and delivery, in addition to the 7 babies who would have been infected during the ante-natal period.

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<sup>2</sup> It must be emphasised that these rates are approximations based on various research studies that have shown different rates of vertical transmission.

The administration of NVP to mother and baby (see second column in the diagram) reduces the rate of intra-partum transmission. Instead of 16 women infecting their children, proper NVP administration will reduce this number to about 6. In other words, with NVP administration, approximately 13 out of a 100 HIV positive women will transmit HIV to their baby (seven before delivery and six around labour).

Several factors influence the risk of transmission during labour and delivery. A high maternal viral load increases the risk (e.g. with newly infected women and women with late-stage HIV infection). Anti-retroviral medication reduces viral load and the risk of transmission. Various obstetric factors also affect the risk of transmission. For example, caesarian sections are protective; traumatic or instrumental deliveries, prolonged labour and a prolonged duration of ruptured membranes are harmful.

However, on average, at the time of birth, the difference between non-intervention and correctly administering NVP during and after labour is that about 10 out of 100 babies born to known HIV positive pregnant women will be saved from HIV infection.

#### *After delivery*

After delivery, HIV transmission occurs through breastfeeding. If breastfeeding is completely avoided, there will be no post-natal transmission of HIV. In a group of a 100 HIV positive pregnant women who receive the correct administration of NVP and who completely avoid any breastfeeding, HIV will be transmitted to 13 out of 100 of their babies (see column 3).

If, on the other hand, breastfeeding continues, the number of children that will be infected will depend on:

- the duration of breastfeeding (the longer the period of breastfeeding, the higher the risk of transmission and the larger the number of children infected);
- whether there is mixed feeding (non-exclusive breast feeding increases the risk of transmission – this is thought to be because mixed feeding causes some reaction in the lining of the intestines which makes it easier for the virus to infect the baby);
- frequency of conditions such as mastitis and cracked nipples which increase the risk of transmission; and
- maternal viral load.

On average, with the normal infant feeding practices described above, approximately six further cases of HIV transmission will occur in the 6 months after delivery (column 1). This figure will increase by a further two by 12 months, resulting in a total HIV transmission rate of approximately 31% 12 months after delivery in the *non-intervention group*.

In the second group, approximately seven further cases of HIV transmission will occur between birth and 6 months through normal infant feeding practices. The number of HIV infections due to breastmilk is slightly higher in the column 2 group because there are a larger number of uninfected babies at risk of HIV infection at the time of birth. If breastfeeding continues after six months, the cumulative number of babies infected will be about 22 at the end of a year (column 2).

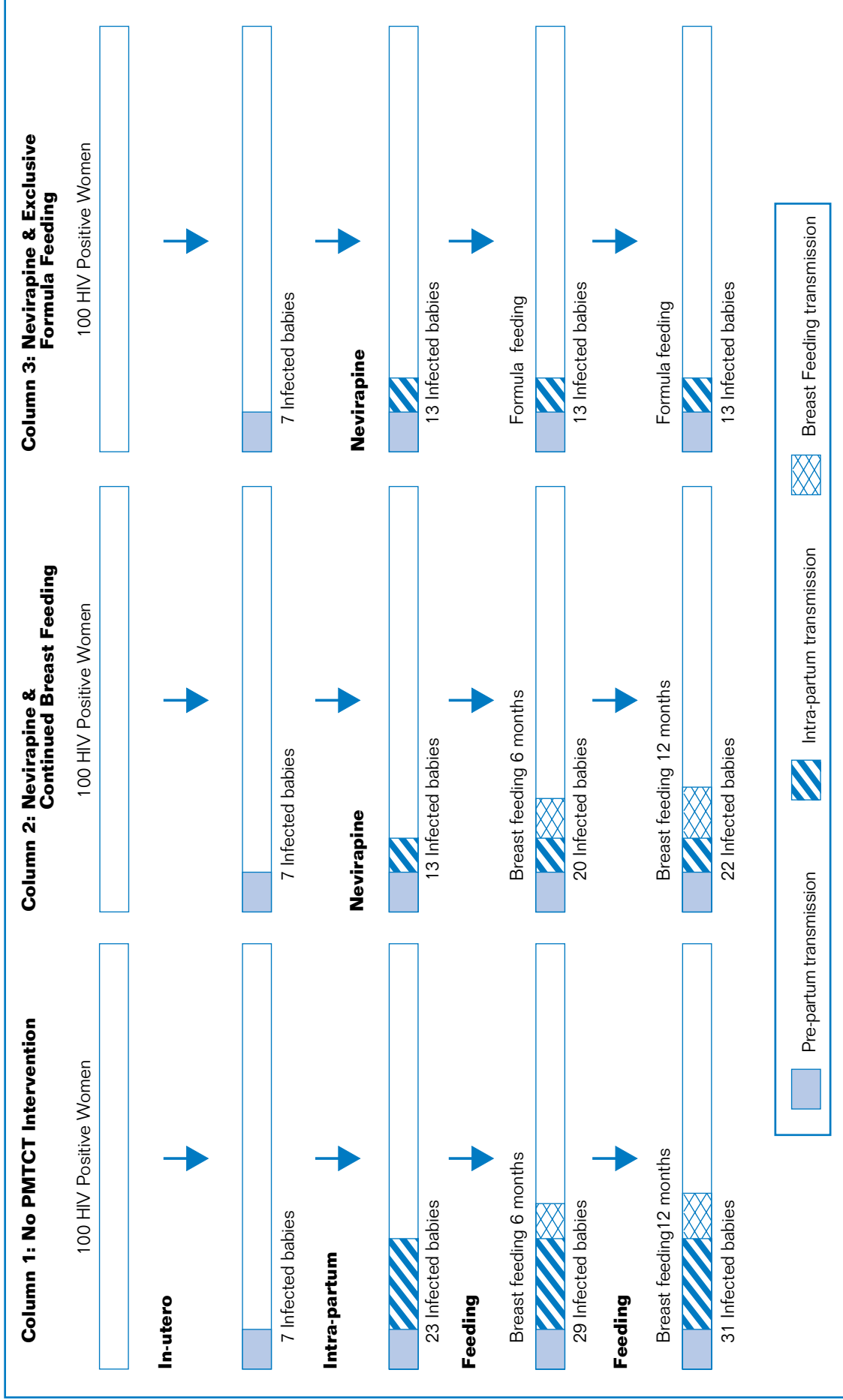
In the ideal world of perfect implementation, where NVP is administered and where women are able to exclusively formula feed safely, overall vertical transmission could be reduced from 29% at 6 months to about 13%. In other words, approximately 16 out of every 100 babies born to HIV positive pregnant women would be protected from HIV infection in a world of perfect implementation.

If, however, there is incomplete coverage of HIV positive women with NVP, unsafe obstetric practices and mixed feeding, the overall transmission rate will be higher than 13% and the number of babies saved from HIV will be less.

The rates of HIV transmission in the two groups that provide breastmilk (columns 1 and 2) could be reduced significantly if breastmilk is provided *exclusively* in the first six months. This would mean that the difference in the numbers of babies protected from HIV between columns 2 and 3 will be less.

The figures described above relate specifically to HIV transmission rates. However, the PMTCT programme also needs to be assessed in terms of its impact on overall child health. Because there is a higher risk of mortality and morbidity associated with formula feeding, the benefits of reducing vertical transmission rates through replacement feeding need to be balanced against the harmful effects of formula feeding.

**Vertical Transmission Rates**



## 6.2 Infant feeding

From the perspective of reducing post-natal HIV transmission, all HIV positive women should be encouraged and supported to provide exclusive formula feeding. The longer a woman breastfeeds, the higher the chance of transmitting HIV to her child (the risk is highest in the first five months of breastfeeding).

With this in mind, the government has offered to provide six months of free formula to all HIV positive mothers should they choose to avoid breastfeeding. However, the avoidance of breastfeeding and the promotion of formula feeding are not without their own risks.

### The benefits of breastfeeding

Breastmilk is the best source of nutrition for the first 4 – 6 months of life. In addition, it provides protection from a number of infectious diseases. Infants who are not breastfed and who receive formula milk, have a 6 fold increased risk of dying in the first 2 months of life; a 4 fold increase between 2-3 months, and a 2.5 fold increase between 4-5 months compared to those who are breastfed.<sup>3</sup> UNICEF estimates that 1.5 million non-HIV related deaths per year can be prevented globally through breastfeeding.<sup>4</sup>

In addition, the unsafe and unhygienic preparation of formula feeding carries the risk of causing diarrhoeal disease, and consequently, malnutrition in infants. A WHO report concluded that full or partial breastfeeding would reduce current childhood deaths from diarrhoea by 66%. In addition, it has been estimated that a 40% increase in breastfeeding in those regions with short breastfeeding duration, such as Latin America, could prevent up to 15% of diarrhoeal deaths.

The benefits of breastfeeding for HIV infected children should also be considered. The 13% of HIV-infected infants at birth (column 2 in previous diagram) are likely to do much better on breastmilk than on formula for the same reasons mentioned above.

Finally, breastfeeding also contributes to reduced fertility and better family spacing, another factor that has been shown to correlate strongly with child mortality and nutrition rates. The desirability of reducing fertility in HIV positive women is a particularly important benefit that will be lost as a consequence of formula feeding.

### Spillover effect

Although the current policy is only to target free formula to women who are HIV positive, there is good reason to be concerned that the promotion of formula feeding through the PMTCT programme could spill-over into the HIV negative population.<sup>5</sup> Evidence of “spill-over” is becoming apparent in Botswana, Kenya, Namibia and Uganda where efforts to promote breastfeeding have declined as a result of formula

<sup>3</sup> WHO collaborative study on the role of breastfeeding on the prevention of Infant mortality. Effect of breastfeeding on infant and child mortality due to infectious diseases in less developed countries: a pooled analysis. *Lancet* 2000; **355**: 451-455.

<sup>4</sup> UNICEF. State of the World's Children 1997. UNICEF, New York, 1997.

<sup>5</sup> Nicoll A, Newell ML, Peckham C, Luo C, Savage F. Infant feeding and HIV-1 infection. *AIDS* 2000; **14** (suppl 3): S57-S74.

feeding interventions to prevent HIV transmission.<sup>6</sup> This effect may be greater when free or subsidised formula is available.

Anecdotal reports from a number of the South African learning sites already suggest two forms of spillover. First, some nurses report that women are providing some of the free formula to siblings and other family members. As with experiences of other “food aid” programmes, supplies may be consumed by other members in the family instead of the intended beneficiary. Secondly, there have been reports that some free formula is being re-cycled and sold off in the community.

### **Assessing risk**

In the context of South Africa’s high prevalence of child malnutrition, high infant mortality rates and continued cholera outbreaks, there is a very real risk that the promotion of formula feeding could do more harm than good in some communities.

The national PMTCT protocol therefore advises nurses to assess the socio-economic, environmental and home circumstances of HIV positive pregnant women during ante-natal counselling in order to help them advise on the safest and most appropriate method of infant feeding. If the risks of formula feeding and non-breastfeeding are considered to outweigh the risks of HIV transmission through breastfeeding, then the HIV positive woman should be advised to *exclusively* breastfeed her child.

However, many nurses and counsellors are struggling to weigh up the relative risks and benefits, and to make reasonably accurate assessments of socio-economic conditions and the feasibility of preparing safe formula feeds. Even where socio-economic conditions are favourable, providing safe and exclusive formula feeding is difficult. Research in Khayelitsha showed the practice of formula feeding to be fraught with difficulties: women received inadequate information about how to make formula feeding safe, and most formula feeds were prepared incorrectly.<sup>7</sup>

Some sites have developed checklists of various factors to help make a more objective assessment of the woman’s circumstances so as to make the right choice. However, the validity, accuracy and effectiveness of these tools still need to be evaluated.

Part of the problem is that the balance of risks between HIV transmission and the harmful effects of formula feeding is simply not known. Although the international tendency has been to promote formula feeding as part of a package of PMTCT services, more people are questioning the appropriateness of this trend, and calling for greater debate.

It is interesting to note that a study from Kenya found that formula-fed infants had a 40% reduction in HIV transmission compared to a group of breastfed infants. However, the overall 24 month mortality rates were similar in both groups. The study also found that during the first 3 months of life, infants in the formula fed group had increased rates of diarrhoea, dehydration and respiratory infections. What is of particular concern is that the mothers recruited for this study had access to clean water, free formula, and

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6 Latham MC, Kisanga O. Breastfeeding and HIV – a four country study. Paper presented at 17th International Congress of Nutrition, Vienna, August 2001, abstract no: 3.03.012.

7 Chopra M, Schaay N, Sanders D, Puoane T, Piwoz E, Dunnett L. HIV and Infant feeding: Summary of findings and recommendations from a formative research study with the Khayelitsha MTCT programme, South Africa. Draft Report, May 2000.

received frequent and regular support in the form of home visits by health workers. This suggests that gains made from preventing mother-to-child transmission of HIV by implementing exclusive formula feeding were negated by deaths from other causes.

### **Social and cultural factors**

Apart from socio-economic considerations, a number of socio-cultural factors affect infant feeding practices. It is apparent that most women provide mixed feeding with breastmilk, and that this practice is informed by traditional socio-cultural norms which are often enforced by older women in the community, particularly mother-in-laws. Women who therefore choose to exclusively breastfeed may face tremendous social pressures at home to mix feed, and actually find that they are unable to implement their choice based on the advice and counselling received.

There are also socio-cultural constraints to the provision of exclusive formula feeding. Many informants, for example, have described the maternal instinct to provide comfort to a crying child by putting her to the breast. This is all the more likely under socio-economic situations where the practical difficulties of boiling water and preparing safe formula feeds, would make putting a crying child to the breast difficult to resist. In addition, the stigma attached to formula feeding can make it difficult for women to carry out their decision to exclusively formula feed.

#### *The cost of formula and making it freely available*

Apart from the dangers of replacing breastmilk with free formula, there are concerns about the policy to provide formula to mothers for free. One reason for this is that those women who cannot afford to purchase free formula are precisely those who are most at risk of the harmful and potentially lethal effects of formula feeding. Although free infant formula reduces the financial burden of replacement feeding, the costs for fuel, collecting water and sterilizing feeding implements have to be met by the woman.

The free provision of formula may instead give underprivileged HIV-infected women a false sense of security in being able to provide safe replacement feeding. Informed and reasoned choice on infant feeding may also be compromised by the fact that formula is free. The mere distribution of formula by health workers may also be seen as an endorsement of the product. Under such conditions, HIV positive women, regardless of their socio-economic conditions, may be more likely to opt for formula feeding for the wrong reasons.<sup>8</sup>

At the present moment is not known if particular types of mixed feeding carry greater risks for HIV transmission. However, it would be reasonable to hypothesise that mixing breastmilk with clean water would be less risky than mixing breastmilk with porridge or formula milk, because the latter two complimentary foods are more likely to cause a reaction of the intestinal lining. The presence of free formula within a culture that strongly endorses and promotes mixed breastfeeding may then lead not only to higher rates of mixed feeding with breastmilk, but more dangerous forms of mixed feeding.

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8 Dabis F, Leroy V, Bequet L, et al. Assessment of peri-partum and post-partum interventions to prevent mother-to-child transmission (PMTCT) of HIV-1 and improve survival in Africa. Presented at the 3rd conference on Global Strategies for the prevention of HIV transmission from mothers to infants, Uganda, September 2001.

Finally, although the formula milk powder is made available to HIV positive women for free, it remains a cost born by society and government. The financial expense of milk powder was estimated in 2000 to range between \$72-\$120 for 6 months supply<sup>9</sup> (and will cost more in rand terms due to the depreciation of the currency), and is not an insignificant amount of money.

Another current debate is whether formula milk should be made freely available to women for longer than six months. The suggestion arises from the fact that after six months of formula feeding, mothers will suddenly lose a substantial source of their infant's nutritional requirements.

From 6-12 months, milk is still the main food for infants, and while babies should receive weaning foods, weaning foods should not replace milk. A child aged 6 - 12 months needs at least 500-800ml milk each day, in addition to other foods. Milk provides 50% or more of the energy, protein and iron, and most of the Vitamin A and C requirements, and may continue to provide up to a third of the energy, protein and iron requirements of children aged 12-24 months.

Many of the HIV positive mothers who have been provided free formula for six months would normally have been breastfeeding for at least up to a year. With the cessation of free formula and the non-availability of breastmilk, the child suddenly becomes at risk of malnutrition, unless the mother is able to afford her own supply of formula and other appropriate foods.

On the other hand, the provision of free formula for more than six months would constitute a significant rise in expenditure and increase the frequency of the harmful effects of formula feeding.

### **Infant feeding choices in the PMTCT sites**

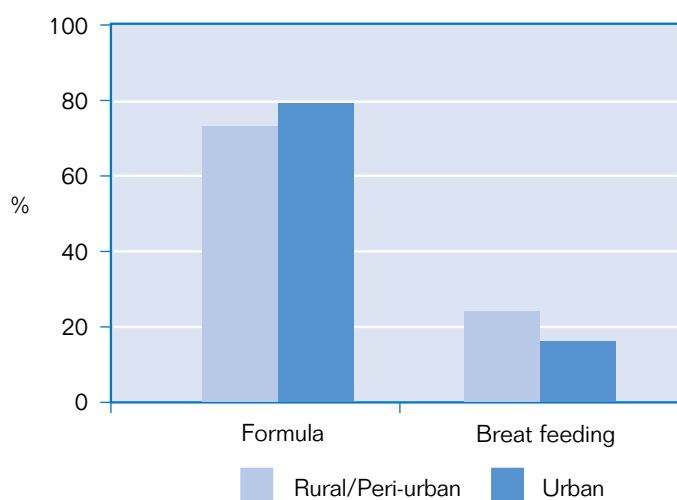
In terms of the actual choices that are made, the data from the routine monitoring system of the PMTCT programme shows a significant variation from site to site. The data refers to feeding choice collected soon after delivery, and is not data on actual feeding practices at home. One must be cautious about these figures as it is probable that the stated preferences of women reflect the views and opinions of providers and programme managers. In other words, patients will say what they think the nurse or counselor wants to hear, rather than what the woman actually thinks or does at home. The table below shows that most women state a preference to formula feed soon after delivery, with a slightly higher proportion of women indicating a preference to breastfeed in the rural sites.

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<sup>9</sup> Wilkinson D, Floyd K, Gilks CF. National and provincial estimated costs and cost effectiveness of a programme to reduce mother-to-child HIV transmission in South Africa. *S Afr Med J.* 2000; 90: 794-8.

Province	Site	Start Date	Rural/Urban	Exclusively formula feeding	Exclusively breast feeding
<b>Gauteng</b>	Natalspruit	May 2001	Urban/Peri-urban	96%	3%
	Kalafong	June 2001	Urban/Peri-urban	85%	15%
<b>Western Cape</b>	Guguletu	Jan 2001	Urban/Peri-urban	95%	4%
	Paarl District	May 2001	Rural/Peri-urban	73%	27%
<b>Northern Province</b>	Mankweng	Aug 2001	Urban/Peri-urban	73%	7%
	Siloam	Mid Nov 2001	Rural	N/A	N/A
<b>Mpumalanga</b>	Shongwe	Sept 2001	Rural	74%	26%
	Evander	Oct 2001	Urban	89%	11%
<b>Free State</b>	Virginia	July 2001	Urban	77%	23%
	Frankfort	Aug 2001	Rural	68%	32%
<b>KwaZulu Natal</b>	Durban	June 2001	Urban	40%	42%
	Pietermaritzburg	June 2001	Rural	65%	35%
<b>Eastern Cape</b>	East London complex	October	Urban	69%	31%
	Umzimkulu	October	Rural	54%	46%
<b>Northern Cape</b>	Kimberley	Aug 2001	Urban	82%	8%
	De Aar	Aug 2001	Rural	100%	0%
<b>North-West</b>	Thlabane	July 2001	Urban	81%	19%
	Lehurutshe	July 2001	Rural	79%	0%

**Comparison of infant feeding choices between Rural/Peri-urban and Urban sites.**



## 6.3 Beyond vertical transmission

Apart from reducing the rate of HIV infection in children, a PMTCT programme has the potential to improve the quality and delivery of other maternal and child health services as well as other HIV sub-programmes.

For example, the PMTCT programme can be implemented in a way that will improve the overall quality of ante-natal and labour ward care. It could also be used to help promote better use of ante-natal care services and earlier booking. The emphasis on the follow-up care of mothers and children could act as a stimulus for improving the general quality of child health care and the clinical care of patients with HIV/AIDS. Ensuring a regular supply of NVP and HIV testing kits, may also address the erratic and irregular supply of other medicines and supplies.

Rectifying the systemic weaknesses of the health care system that are currently constraining the effective and efficient delivery of PMTCT services would benefit other services. The PMTCT programme could therefore be used as a catalyst for addressing generic deficiencies such as the poor physical infra-structure of health facilities and inadequate staffing levels.

By striving to create an optimal PMTCT programme, the communication, linkages and referral systems between mobiles, clinics, CHCs, MOUs and hospitals would be strengthened and improve the general efficiency and effectiveness of the health care system.

Fourthly, any actions and commitment towards reducing the vertical transmission of HIV *without* other actions and commitment to make it possible for HIV positive mothers to provide safe formula feeding *and* on-going child care should be untenable. In this way the PMTCT programme can accentuate the imperative for the basic needs of all households to be met.

Finally, and of huge significance is the potential for the PMTCT programme to break through the denial and stigma of HIV within communities. By linking a tangible benefit to HIV testing, the PMTCT programme can help bring HIV much more into the open, and confront communities with the reality of the epidemic. By emphasizing couple counselling and testing within the PMTCT programme, there is also a potential for directly addressing HIV with men. The lay counselors that are recruited and trained through the PMTCT programme will also be resources for the education and mobilization of their communities. In this way, the PMTCT programme can act as an engine for broader HIV prevention.

On the other hand, a PMTCT programme that is implemented narrowly and vertically could undermine the development of the health care system and the delivery of integrated health services. Resources could also be diverted away from interventions that would have a bigger positive impact on overall health.

# CONCLUSIONS AND RECOMMENDATIONS

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## 7.1 ADDRESSING THE ISSUES OF SYSTEMS AND INFRA-STRUCTURE

PMTCT implementation varies between provinces and from site to site considerably. Some provinces and sites are doing well, whilst others are struggling.

Those sites that are struggling to provide good PMTCT services tend to be those that operate within a context of poor health care delivery in general and a poorly functioning health care system. At the core of the differences between sites and provinces are the large inequities in health care infra-structure within the country.

The differential level of capacity between some of the urban sites (with academic / tertiary support, good physical infra-structure and adequate staffing levels) and some of the rural sites (where several clinics lack electricity, working telephones, space and adequate staffing levels and where hospitals may lack, amongst other things, sufficient doctors) is large. The moral and political imperative of preventing mother-to-child HIV transmission offers South Africa an opportunity to redress the unacceptable inequities within the health care system with more vigour and urgency.

Many of the difficulties and constraints identified in the pilot sites are systemic in nature, and relate to the functionality of the health care system as a whole (as opposed to the functionality of the PMTCT programme specifically). In order to improve the quality and sustainability of PMTCT services, and to ensure that any expansion of PMTCT services runs smoothly, these systemic issues must be addressed.

Because of the significant differences in functionality and health care infra-structure between provinces, recommendations and actions to improve the current PMTCT services, as well as an expansion of the programme, should be developed on a province by province basis.

It is useful to consider the issue of systems and health care infra-structure in terms of three dimensions:

- Human infra-structure
- Physical infra-structure
- Management infra-structure

### **Human infra-structure**

The presence and availability of adequate human infra-structure is the most important ingredient of a successful PMTCT programme. The term “human infra-structure” incorporates staffing levels, staffing mix and staff competencies and motivation.

#### *Staffing levels*

Services that run with inadequate staff don't run well. In all facilities, the PMTCT programme has entailed an increase in workload and clinical responsibilities. In a few sites, this additional workload has not been compensated by any additional staff, and has resulted in stress and possibly, a deterioration in the overall quality of care provided. In most sites the PMTCT programme has been accompanied by the recruitment of lay counselors, although some sites still do not have enough lay counsellors. Nurse and medical staffing levels have been mostly unchanged.

In order to sustain the current PMTCT programme, as well as expand it to new sites, minimum staffing levels for midwives, nurses, doctors and lay HIV workers need to be established for clinics and hospitals, based on workload and need. The national and provincial Departments of Health, particularly their Human Resource Directorates, must then be tasked with developing and implementing a plan to reach these staffing levels.

Minimum staffing levels for PMTCT counseling should be based on the following norms: Initial pre- and post-test counseling - average of 60 minutes per client; follow-up counselling and support - an average of 30 minutes per visit on two separate occasions for HIV positive women; a maximum of 8 clients seen per day per counselor.

#### *Staff mix*

Lay counsellors are a critical element of the PMTCT programme (as well as of other programmes within the broader national HIV strategy). The recruitment and training of lay HIV counsellors to work in close collaboration with professional staff has been a very positive feature of the PMTCT programme.

The lack of coordination and consistency in the management, training and remuneration of different kinds of lay workers needs to be addressed. One recommendation is to move towards the concept of generic “lay community HIV workers” who would form a pool of human resources at the sub-district level to support the full range of HIV/TB sub-programmes in a more integrated manner.

Although the quality of service provided by lay counsellors has not been formally evaluated, it is clear that they provide a critical service. However, it is important to note that a comprehensive PMTCT programme requires a mix of clinic nurses, midwives, obstetric and paediatric ward staff and doctors playing complimentary roles. In some sites, the involvement and support of doctors who should be providing important

clinical leadership within the PMTCT programme, needs to be improved. In addition, the post-partum care and support of mothers with HIV and their children requires better links between PMTCT services with welfare and nutrition staff.

#### *Staff competencies, morale and motivation*

Training and human capacity development is critical for the development of adequate staff competencies, morale and motivation. Unfortunately, many staff do not have a strong foundation of knowledge and skills in HIV and PHC. Extensive and fairly lengthy training interventions have therefore been required, and arranging this has required a big effort. In many sites, despite major training efforts, not all relevant staff have been covered. The sheer volume of training required in the pilot sites points to a major challenge should provinces expand the programme to new sites.

A number of lessons have been learnt about training. In terms of content, there is a need to balance the focus on HIV counselling and testing with more training on infant feeding and child health. Off-site, formal classroom-based training needs to be complimented with more on-site, in-service training with a focus on skills development, local problem solving and on changing attitudes towards HIV.

Without regular support and supervision of front-line staff, the positive impact of training is not sustained. Support and supervision, as well as organising peer support groups, is required to help prevent staff burn-out. Providing effective and appropriate support and supervision to front-line staff is a highly skilled job that should also be part of a human resource development plan.

A pool of experts and trainers with the commitment and time to provide training is needed in each province, especially if the PMTCT programme is to be expanded. The availability of skilled clinicians capable of providing good care to HIV positive mothers is limited, especially in the rural areas. Clinicians in academic / tertiary institutions with HIV expertise should be deployed to develop capacity in district hospitals and rural areas through outreach programmes.

Finally, a strategy to ensure that HIV counseling, PMTCT and infant feeding is taught thoroughly and effectively in all under-graduate nurse and medical training institutions must be developed and implemented immediately.

### **Management infra-structure**

Good management and a functional provincial DoH is a key factor determining the success, efficiency, effectiveness and sustainability of the PMTCT programme. Provincial leadership has been shown to make a big difference. Where senior managers have taken an active interest in the PMTCT programme, faster and more effective implementation has usually followed.

Senior managers are important for integrating the programme horizontally across the department and creating an enabling bureaucratic environment for programmatic staff. In some provinces and sites, tension between personalities and conflict about roles and responsibilities amongst managers has impeded progress with implementation. On the other hand, provinces with effective multi-departmental steering committees were able to establish support systems that helped make the sites work.

Strong technical capacity and the presence of experienced clinicians with a commitment to HIV within the provincial PMTCT management structures is also an important component of provincial capacity.

At the site level, effective sub-district leadership and management as well as the presence of a PMTCT driver is important. The support and involvement of local medical staff, the sub-district HIV, MCH and HIS managers and hospital matrons are equally important. The lack of integration between hospitals and clinics, or between local authority and provincial facilities, undermines the programme. All this requires effective and integrated management at the sub-district level.

NGOs are important potential role-players in the recruitment, training, remuneration, support and supervision of lay counselors. The importance and benefit of local PWA support groups has also been noted in several facilities. A more pro-active development of NGOs and PWA support groups in those sites that currently lack them is recommended. However, it will be necessary to improve the capacity within the DoH to work with NGOs efficiently, effectively and in the spirit of partnership.

Effective management is dependent on the availability of accurate and relevant data and information. Although the quality of data is improving, in most provinces and sites, there is a need to strengthen data capture, data management and programme evaluation skills.

Uncoordinated training, the maldistribution of staff and inappropriate staff rotation policies point to the need for improved human resource management at all levels of the health system.

The fact that many provinces did not develop site-specific plans and budgets, as well as the lack of reporting to Pretoria on the national grant, suggests a need to strengthen financial management.

Finally, the slow progress with the establishment of functional health sub-districts with decentralised management structures capable of integrating PHC delivery is a weakness that will also constrain any expansion of the PMTCT programme. This requires the public health care sector to urgently speed up its structural re-organisation, and the establishment of a functional “sub-district health system”.

#### *Physical infra-structure*

The importance of physical infra-structure has been reflected in two ways. First of all, the inadequate amount of physical space and privacy has hampered the ability of many facilities to provide adequate counselling and HIV testing services. Many provinces have therefore spent substantial amounts of money to renovate facilities or establish new spaces.

In addition, the lack of physical infra-structure has been felt in terms of access to facilities. In many of the rural sites, the difficulties and expense of simply getting to health facilities that provide ante-natal, delivery and post-natal care remain major barriers to adequate coverage of the programme as well as to adequate continuity of care.

Provinces need to plan and budget for the creation of adequate space for HIV counselling and testing services in other sites.

## 7.2 Improving the quality of PMTCT services

### Counselling and testing

The uptake of HIV testing is a rate-limiting step within the PMTCT programme. The recruitment of lay counselors to assist with HIV counseling and testing has therefore received a great deal of attention. The term “counseling” has consequently become strongly associated with the gaining of consent for an HIV test. However, other dimensions of counselling need to be strengthened. These include the empowerment of women with clear and accessible information about HIV/AIDS, childbirth, child care and infant nutrition; advice and information about social security entitlements and sources of community support; on-going emotional and psychological support to women who now have to live with the knowledge of being HIV positive; and advice to women about disclosure.

Efforts and capacity to provide ‘couple HIV testing’ as well as community-targeted interventions to address stigma, ignorance and prejudice in the community, also need to be strengthened as adjuncts to the services targeting pregnant women. In this way the PMTCT programme can become a potent adult HIV prevention programme.

Finally, on a practical note, the option of using rapid saliva tests as an alternative to rapid blood spot tests should be explored as this could relieve some of the workload on professional staff.

### Care during labour

In terms of clinical policy, there are no reasons to question the clinical efficacy of NVP and the international consensus that the drug is safe and sound. The main recommendation related to NVP is to implement some operational research to determine whether:

- NVP is dispensed and actually self-administered correctly
- midwives and doctors pro-actively ask women about their HIV status and self-administration of NVP during labour (so as to avoid “missed opportunities”)
- labour wards are able to provide adequate patient confidentiality and privacy regarding HIV status

In addition, clearer policies and guidelines on the clinical management of HIV positive women in labour and the appropriateness of applying revised obstetric guidelines universally are required. The potential impact of revised obstetric practices resulting in higher caesarian sections should also be monitored.

A rapid audit of obstetric care and the continuity of care between the labour ward and the post-natal care of babies is being conducted in a sample of labour wards, and will provide a clearer picture of these issues soon.

Finally, the clinical guidelines on the timing of the paediatric dose of NVP after delivery needs to be reviewed given that many women leave the health facility within 24 hours of delivery.

## Post-partum care

The policy and guidelines on the post-partum care of children born of women with HIV needs to be looked at again as current guidelines are largely unrealistic. Sites should rather develop their own targets for follow-up care that are realistic and feasible.

Patient held records are essential for adequate continuity of care. At the present moment, the need to protect patient confidentiality about HIV status is given greater weight than the need to promote continuity of care and encourage a greater openness about HIV status within the health care setting.

Several public health specialists have been questioning the appropriateness of prescribing prophylactic trimethoprim. Unless there are sound public health grounds for doing so, the DoH may want to re-consider this policy. Using trimethoprim as an incentive for attending follow-up care is inappropriate.

### 7.3 Using the PMTCT programme as an engine for improving the quality of health care

As described earlier, the PMTCT programme incorporates a unique collection of services and activities that when put together, has the potential to act as an engine or catalyst for the improvement of primary health care services in general.

Apart from demanding an improvement of the infra-structure of the health care system, as described above, the PMTCT programme can help catalyse the improvement of clinical aspects of the health care system. By acting as an entry point for improving the quality of:

- obstetric services
- HIV counseling and post-test care and support
- clinical care for patient with HIV/AIDS
- child health care and nutrition

Linking the PMTCT programme to these other areas of patient care is important not just to maximise the full potential of the programme, but also to help avoid the possible “neglect” of other essential maternal and child health services. Failing to conceptualize the PMTCT programme in this broader and catalytic role could represent a tremendous missed opportunity for the country.

While it would be tempting to adopt a rapid and vertical approach to the immediate coverage of PMTCT services across the country, a slower but ultimately more effective and more sustainable approach could realise the potential for the PMTCT programme to revitalize the entire health care system, invigorate the broader HIV / AIDS programme and raise the general standard of maternal and child health services. This would not only benefit the broader population, but is of particular importance for the post-natal care and well-being of the mother-child clients of the PMTCT programme who will be receiving this care from the general PHC services. However, the case for expanding the PMTCT programme in a holistic and systems-building manner should not be interpreted or used as an argument for inaction and delay in expanding the

state's capacity to prevent mother-to-child transmission.

## 7.4 Infant feeding

With all the publicity surrounding government's position on anti-retrovirals, the more important and serious issue of its policy on infant feeding and providing free formula has been neglected. Infant feeding is probably *the* major policy issue for the government.

The current policy to provide free formula needs to be reconsidered. There is a real danger that it may do more harm than good in many communities. While the long-term aim is to make it possible for all HIV positive women to provide safe and affordable *exclusive* formula feeding, under the current social, economic, environmental and cultural circumstances, the policy may contribute to higher rates of mortality and morbidity due to other diseases, as well as higher rates of mixed feeding.

A national commission of experts should be urgently set up to discuss infant feeding in the context of HIV and mother-to-child transmission. There is a very delicate balance between avoiding HIV transmission through breastfeeding with avoiding the harmful effects of promoting free formula.

Some public health specialists would recommend that the DoH no longer make formula freely available, but continue to thoroughly inform all women about the risks and benefits of different feeding options, and encourage exclusive formula feeding only for those mothers who are able to afford the formula themselves. Such a policy should be also complimented with a strategy to enable women to provide *exclusive* breastfeeding (as opposed to the norm of mixed feeding with breastmilk). Other public health specialists would recommend that government continue to provide free formula, but to target this to communities and households that would be able to exclusively formula feed safely.

An option that should receive serious attention is the post-natal administration of anti-retroviral medication to mothers and/or babies as a deliberate strategy for making breastfeeding a safe option.

If formula is going to continue to be made available for free, it is then obligatory that it is made easily accessible. While it may be unwise to provide a full six months worth of free formula to a mother on discharge, it would be wrong to provide an initial supply of formula and then make it expensive and difficult to receive continued supplies.

Finally, the imperative to save babies from HIV should also provoke a much broader and urgent response from the government and civil society to address the unacceptable levels of child poverty and mortality due to preventable causes. The commission should therefore adopt a broader perspective that incorporates the country's response to household food security, poverty alleviation, access to social welfare grants, care systems for orphans and the provision of clean water to all households.

## 7.5 Expanding the PMTCT programme

The initial focus on two learning sites per province has given national and provincial management the opportunity to learn from their experiences, as well as improve the PMTCT guidelines. There have been many lessons learnt, as well as the development of training and IEC materials and tools to support programme management.

With this in mind, there are now no good reasons for delaying the gradual and phased expansion of PMTCT services.

Given the differences in capacity and infra-structure, it would be reasonable for provinces to expand the provision of PMTCT services at different speeds. What is important is for the expansion to be properly planned, implemented strategically and systematically and that it takes into account the many lessons that have been learned.

For provinces that are currently struggling with implementation in their two learning sites, a plan for expansion should include and begin with a strengthening of provincial management and support structures and the continued improvement of services in the learning sites. These provinces should be targeted by the national DoH for support and capacity development.


Plans for expansion must also address the many systemic and infra-structural constraints that have been identified in order to avoid a multiplication of poor and / or non-sustained service delivery, as well as to reduce the levels of health care inequity. The lack of optimal health systems infra-structure is therefore *not* a reason for delaying the expansion of PMTCT services, but should rather inform the strategic expansion of PMTCT services. Without paying some attention to the systems and infra-structure issues, the expansion of PMTCT services may not be cost effective or sustainable. In addition, leaving the poor state of health care infra-structure unattended to in many parts of the country will result in the existing inequities in health care being widened even further by an expansion of PMTCT services.

A more appropriate budgeting formula will be required to ensure that sites and provinces that are historically under-resourced receive a more equitable share of funding and support should there be an expansion of the programme. The 'gap' between existing resources and a minimum standard of health care infra-structure (especially in terms of human resources) should be measured in every sub-district across the country to ensure that this is addressed in the fullness of time.

With coherent and committed political and senior management leadership at the national and provincial levels, it should be possible for all provinces to begin implementing PMTCT services in some new sites by the middle of 2002.

The variation in health care infrastructure, geography, population density, HIV prevalence and socio-economic status necessitates a more context-based approach to planning and implementation. Local conditions and problems require local solutions. The formation of an effective "sub-district health system" offers the best organisational framework for the delivery of PMTCT services and of PHC in general.

In order for provinces to gradually expand the provision of PMTCT services, as individual sites 'mature', provincial management should hand over the day-to-day management of PMTCT services and their on-going development to district and sub-district management structures. With the provincial office increasingly playing a



supportive and monitoring role, sub-district and district health management teams should implement continuous quality improvement cycles based on routine monitoring and local operational research. Implementation in this regard can be considered as an on-going process of continual improvement.

The PMTCT programme demonstrates the need to integrate community-based, clinic, CHC and hospital care as part of a seamless continuum of care. Any expansion of the PMTCT programme should therefore be based on a sub-district model. Targeting individual facilities, as opposed to sub-district areas, for any expansion of PMTCT services should ideally be resisted. Planning the expansion of the PMTCT programme on the basis of “health sub-districts” will also offer a better framework for addressing the many systemic issues at the same time.

A phased and systematic expansion of comprehensive PMTCT services should be combined with the *immediate* provision of NVP to pregnant women already known to be HIV positive. However, in doing so, it would be important to avoid reinforcing the current portrayal of the PMTCT programme as being only about the administration of NVP.

Finally, there is still a need to continue to learn from the 18 learning sites, and these sites should continue to host in-depth research